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Points of Interest

Healthcare for men and women with learning disabilities: understanding inequalities in access

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- There is considerable concern in the UK over the quality of the healthcare received by people with learning disabilities.
- Mencap's report *Death by Indifference* followed by the Michaels's report *Healthcare for All* and the Ombudsman's report *Six Lives* have put access to healthcare for people with learning disabilities on the political map.
- These reports document healthcare providers failures to comply with equalities legislation.
- Our own small-scale research shows that access to healthcare for men and women is crucially dependent upon *support* from family carers, and professionals in health and social care.
- Access to healthcare for people with learning disabilities is a complex issue straddling legal duties toward all people with impairments; the interactional intimacies of providing support to people with learning disabilities, and concerns over the quality of care provider to all patients, not just those recognised as disabled.

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Abstract

Healthcare for men and women with learning disabilities (known internationally as Intellectual disabilities) has risen up the political agenda in the UK, propelled there by a report from the charity ‘Mencap’, *Death by Indifference*. This has resulted in a renewed effort, set out in the policy document for England ‘*Valuing People Now*’, to ensure that people with learning disabilities receive the healthcare and support they need to live healthy lives. This paper, drawing upon experience in England, describes the challenges of providing healthcare to men and women with learning disabilities; reviews *Death by Indifference* and the reports produced in its aftermath, *Healthcare for All* and *Six Lives*; presents findings from a small-scale study of access to healthcare undertaken in the East of England; and concludes with a discussion of whether the recommendations made in *Healthcare for All*, and accepted in *Valuing People Now*, will improve healthcare for men and women with learning disabilities.

Keywords: healthcare, learning disability, learning disabilities, inequality, access

**Healthcare for men and women with learning disabilities:
understanding inequalities in access**

Introduction

Healthcare in the United Kingdom (UK) has become inextricably linked to reforms of the National Health Service (Department of Health, 1989, 1997, 2010a). Irrespective of which political party has been in government in the UK, reforms have been proposed to reduce inefficiency, doing more with less, while at the same time raising standards of patient care through the promotion of choice. Healthcare, predominately delivered through the National Health Service (NHS), is being personalised like other public services (Department of Health, 2007, 2010a). Not only is individual patient consent central to the giving of treatment, but it is also now expected that patients should have greater opportunity to choose between treatments, and between clinicians and healthcare providers (Department of Health, 2010a). Alongside the promotion of patient choice is a growing emphasis on equality and human rights (see NHS Constitution (Department of Health, 2010c)). Appropriately, healthcare providers and practitioners, in line with the *Human Rights Act 1998* and equality legislation (the *Disability Discrimination Act 1995* and the *Equality Act 2010*), are required to treat all patients with dignity and without discrimination. Where patients have a disability, those working in organisations responsible for their care and treatment are legally required to make ‘reasonable adjustments’, ensuring that all patients, regardless of any impairments or disabilities, have equal access to healthcare. Throughout the NHS in the UK these developments have increasingly been linked to concerns over patient experience and outcomes (Hunter, 2008). It is presumed that the interests of patients

(rather than the factional interests of healthcare providers and professionals) are best served by promoting patient choice (albeit in consultation with clinicians) because the collective consequence of individual patient choice is institutional reform - a health service better able to meet patients' needs. Can, however, the latest wave of reforms meet the needs of patients with learning disabilities, a group of patients whose often complex health were overlooked until the publication of *Death by Indifference* (Mencap, 2007)? This report not only prompted a public inquiry and an investigation by the Health Ombudsmen, but also led to a new policy initiative to improve access to healthcare for this population.

In considering these issues we have divided our paper into four parts: the first briefly describes the challenges of providing healthcare to men and women with learning disabilities; the second reviews *Death By Indifference* and its aftermath that led to this new policy initiative; the third presents findings from a small-scale interview study of access to healthcare; and the final part concludes with an assessment of whether or not healthcare for men and women with learning disabilities is likely to improve.

Providing healthcare to men and women with learning disabilities

Measured either in terms of mortality and morbidity rates (Hollins, Attard, von Fraunhofer, McGuigan, & Sedgwick, 1998; McGuigan, Hollins, & Attard, 1995) or levels of unmet need (Cooper et al., 2006), men and women with learning disabilities have poorer health than their non-disabled peers. Just like their non-disabled peers, adults in the UK with learning disabilities access primary healthcare through General Practice (GP) surgeries, and access secondary healthcare through general hospitals and community mental health services. In addition, on account of their potentially

complex disabilities and associated illnesses, they are also entitled to support from specialist community learning disability services. This additional specialist service is an explicit recognition that for some health conditions, most notably epilepsy (Ring et al., 2009), the management of assisted eating and drinking where there is substantial risk of aspirational pneumonia (Chadwick, Jolliffe, & Goldbart, 2003) and mental health and behaviour problems (Krahn, Hammond, & Turner, 2006), the needs of this population require a different, and invariably multidisciplinary, approach from that offered to the general population.

This tripartite division of healthcare can, however, lead to confusion because of uncertainties as to where the boundaries of such services lie, and under what circumstances people with learning disabilities should be accessing care from a secondary service or a specialist learning disability service. Where uncertainty prevails patients are known to ‘fall’ between services, and situations may arise where no single clinician or service has overall responsibility for a patient’s care and treatment. In addition, many men and woman with learning disabilities are reliant upon others articulating their health needs, arranging and facilitating appointments, and ensuring, for example, that treatments plans are followed. In effect, people with learning disabilities may receive their healthcare by ‘proxy’ (Cooper et al., 2006). This also can lead to problems either because a proxy (usually a family or paid carer) is unreliable, or because clinicians are not involving the proxy through either not seeking information from the proxy or not passing on information relevant to the person’s care and treatment. Where patients are thought to lack the capacity to give (or withhold) consent to care or treatment, and healthcare practitioners are unfamiliar

with legal procedures for making substitute decisions, delays in initiating a course of treatment may follow.

People with learning disabilities may have to endure communication difficulties; undergo anxiety provoking changes to their routines as a result of being unwell, and/or may exhibit challenging behaviour. These factors may result in patients with learning disabilities being unable to give reliable reports of their symptoms and/or being unable to deal with examinations, investigations, and/or treatments. Diagnostic overshadowing is an additional risk, whereby people's symptoms are wrongly attributed to their disability rather than to an underlying new illness. It may also be the case that there is the belief, with illnesses such as cancer, that the balance is in favour of not treating (even when treatment is predicted to be very effective) because of the likely intrusive and distressing nature of investigations and treatment, and because the lives of disabled people may be considered to be of limited quality (BBC Radio 4, 2007)

These, then, are the kinds of barriers people with learning disabilities face when accessing healthcare; barriers that are thought to, at least partially, explain this population's higher morbidity and mortality rates, and their high levels of unmet health needs. Furthermore, the complex needs of these patients, coupled to patterns of illness different from those of the general population (Cooper et al., 2006), will disadvantage them in a system designed around majority needs (Heyman, Swain, & Gillman, 2004). However, this disadvantage has in different parts of the UK been both recognised and, at least in principle, addressed. In England, the Disability Discrimination Act (DDA replaced by the *Equality Act 2010*) requires public bodies

to make ‘reasonable adjustments’ to their premises, policies and procedures so as to ensure equality for all; the *Human Rights Act 1998* equally emphasis dignity and respect for all; and the Disability Equality Scheme (under the amended *DDA 2005*) requires that all public bodies produce a disability equality scheme. All of these should address many barriers to access. In addition, *Valuing People* (Department of Health, 2001), the strategy for learning disabilities in the 21st century for England, sets targets for introducing health facilitators whose role is to enable access to healthcare; to register all adults with a learning disability with a GP; and to provide all adults with a learning disability with a health action plan. However, despite the existence of this legal framework and the *Valuing People* targets, it is widely accepted that men and woman with learning disabilities are receiving sub-standard healthcare that results in *avoidable* morbidity and mortality. A body of evidence, some of it research based and some anecdotal, has been published (Disability Rights Commission, 2005; Mencap, 2004) but largely neglected, until Mencap published *Death by Indifference* in 2007. This report, describing the deaths in hospital of six adults with learning disabilities, prompted an investigation by the Health Services Ombudsman and a public inquiry chaired by Sir Jonathon Michael. *Death by Indifference* delivered a shocking and simple message: a remediable injustice was being perpetrated against a vulnerable population.

Death by Indifference and its aftermath

Mencap attributed the six deaths reported in *Death by Indifference* to deficiencies in the care received by these patients. They argued that practitioners were slow in diagnosis and initiating treatment; the concerns of family carers were ignored; nutrition and pain relief was inadequate; procedures for making lawful substitute

decisions were poorly understood; and the ‘reasonable adjustments’ that would have ensured equitable care and treatment were not made. This was, Mencap asserted, a *prima facie* case of ‘institutional discrimination’: the NHS was doing nothing to deal with ignorance and prejudice within its workforce and was failing to make the necessary and legally required adjustments that would provide patients with learning disabilities the standard of care they were entitled to. Furthermore, the report asserted that within the NHS the health of people with learning disabilities was a low priority. *Death By Indifference* echoed an earlier report *Treat Me Right* (Mencap, 2004) by calling for compliance with the DDA; improved training for staff in learning disabilities, and annual health checks for people with learning disabilities. In addition, it called for an independent investigation into the six deaths (because of a failing in the NHS complaints procedures) along with a confidential enquiry into all premature deaths of people with learning disabilities. In May 2007, two months after the publication of *Death by Indifference*, the Secretary of State for Health for the Government announced that the Health Service Ombudsman would investigate the circumstances of the six people who died, and that Sir Jonathon Michaels would chair an independent inquiry into healthcare for people with learning disabilities. The independent inquiry published its report, *Health Care for All*, in July 2008, followed in March 2009 by the Ombudsman’s report, *Six Lives*.

Healthcare for All confirmed the widely held view that men and woman with learning disabilities receive less effective healthcare than the general population, resulting in *avoidable* morbidity and mortality. There was, furthermore, evidence to suggest widespread discrimination against, and abuse and neglect of, patients with learning disabilities. This shocking observation was attributed to ‘poor practice’, with

healthcare practitioners being unaware of: (i) the special needs of patients with learning disabilities; (ii) the importance of communicating with their carers; and (iii) the legislation and guidance that should have prevented discrimination against disabled patients. The inquiry also found that health and social care services were unable to plan and evaluate healthcare for people with learning disabilities because of a lack of information, and that the introduction of health action plans and annual health checks was hampered by confusion as to the precise meanings of these terms.

There was evidence of good practice: training initiatives where staff could learn more about the effects of having a learning disability; the introduction of 'passports' informing ward staff of patients' (dis)abilities and special needs; and the introduction of liaison nurses to guide staff on acute hospital wards in how to make the necessary 'reasonable adjustments'. However, good practice, where it was found, stemmed not from centrally coordinated efforts to improve the healthcare of patients with learning disabilities, but from the initiative of energetic individuals. *Health Care for All* made ten recommendations addressing: (i) the collection and dissemination of information and data on the health and health needs of people with learning disabilities (Recommendations 2, 5), including a Public Health Observatory for learning disabilities, and commissioning a Confidential Enquiry into avoidable deaths of people with learning disabilities; (ii) improvements in communication with, and the involvement of both people with learning disabilities and their carers, in the delivery and design of healthcare (Recommendations 1, 3, 4, 9, 10); and (iii) changes to the commissioning and regulation of health services so as to ensure reasonable adjustments are made and audited (Recommendation 6, 7, 8, 10). The government's acceptance of all ten of these recommendations was formally announced in January

2009 with the publication of *Valuing People Now* (Department of Health, 2009), its revised three year strategy for learning disabilities.

The Ombudsman's report, *Six Lives* (Local Government Ombudsman & Health Service Ombudsman, 2009), investigated the six deaths reported in *Death by Indifference* while also seeking to identify lessons that might usefully inform both health and social care provision. The six deaths revealed what the Ombudsmen described as, 'significant and distressing failures in services across both health and social care'. In four of these deaths the Ombudsman upheld Mencap's complaint that these people had received less favourable care and treatment on account of their disabilities. However, the poor quality care and treatment received by these patients was thought to have arisen from 'maladministration' – the inability of the organisations concerned to adapt to the individual needs of patients. This was specifically attributed to an absence of clinical leadership resulting in patients' needs being overlooked; failures to comply with human rights and equalities legislation, and, in some cases, standards of care that were failing everyone, not just patients with learning disabilities. The Ombudsmen found no evidence to suggest any intentional desire to humiliate or debase people with learning disabilities, and considered only one of the six deaths to have been avoidable. In reaching this conclusion the Ombudsmen endorsed Mencap's implicit charge of 'indifference', but not of institutional discrimination. During the course of her investigation the Ombudsman found examples of good practice but, as in *Healthcare for All*, it was patchy and sprang from committed individuals rather than any coordinated efforts by a service to improve the healthcare of patients with learning disabilities. The Ombudsman made three recommendations, very similar to those made in *Healthcare for All*: (i) NHS and

social care organisations should review their systems for meeting the special needs of people with learning disabilities, including how they involve families; (ii) those organisations with responsibility for regulating and measuring the performance of health and social care providers (the Care Quality Commission, Monitor, and the Equality and Human Rights Commission) should ensure that service providers fulfil their statutory and regulatory duties; and (iii) that the Department of Health monitor progress on these two recommendations.

Since the publication of *Death by Indifference*, the health inequalities experienced by men and women with learning disabilities have risen rapidly up the political agenda. Although there is a significant difference in emphasis between ‘institutional discrimination’ as alleged by Mencap; ‘poor practices’ as identified in *Healthcare for All*, and ‘maladministration’ as found by the Ombudsman, there is much that these three reports have in common. Namely, that as a result of non-compliance with equalities legislation: men and women with learning disabilities received poorer quality healthcare than they are entitled to; there is a general lack of awareness or indifference to the special needs of patients with learning disabilities in secondary care; and carers who are often there to advocate on a patient’s behalf are being ignored by healthcare professionals. Not surprisingly, given these similarities, the recommendations made in the reports are also broadly the same and based on a need for a greater appreciation of the special needs of people with learning disabilities, a requirement that healthcare professionals and provider organisations should comply with equalities legislation, and that compliance should be regulated and monitored. A similarity between *Healthcare for All* and *Six Lives* that we find interesting and noteworthy is the role that committed individuals are said to play as drivers of good

practice. Their role appears especially important as recent reports monitoring progress on the recommendations made in *Healthcare for All* and *Six Lives* have concluded that people with learning disabilities are still not receiving an acceptable standard of healthcare (Department of Health, 2010b, 2010d). With a view to gaining some insight as to why committed individuals are important to ensuring people with learning disabilities receive the healthcare they are entitled to, and to understand why the beneficial effects of the recommendations are seemingly slow to appear, we undertook a small study of access to healthcare.

Access to healthcare

The study, undertaken in the East of England, centred on the catchment area of a single specialist learning disability service. This specialist service is under local authority leadership as it forms part of a Learning Disability Partnership (LDP) that brings together both specialist learning disability health teams and adult social care services. Ten research participants were recruited from each of the following occupations: managers of residential accommodation; GPs; learning disability nurses in the specialist community service; and care managers in the LDP. In addition, four vulnerable patients' leads were recruited from four general hospitals serving the area covered by the LDP. The research participants were interviewed using a semi-structured interview schedule designed to elicit their views on the challenges of healthcare for people with learning disabilities, and how the health of this population might be improved. Where practical interviews were conducted face-to-face they lasted from between 20 to 30 minutes, and all answers were recorded contemporaneously by hand. Where it was not possible to interview respondents in person they were interviewed over the telephone. The written records of the

interviews were examined for content, with emergent themes identified and coded (Cirourel, 1964). The research was giving ethical approval by an NHS Research Ethics Committee (www.nres.npsa.nhs.uk). Our findings are listed below and are followed by a concluding summary.

The managers of residential accommodation we spoke to saw themselves and their staff as having responsibility for monitoring residents' health, administering medication, and arranging appointments with GPs. Responsibilities that were discharged best were where there was continuity of care, something that was easily undermined due to high rates of staff turnover. These managers also identified unresolved tensions around respecting residents' autonomy and independence; such as whether residents' dietary choices, which were invariably poor, should be respected, and whether residents routinely should be accompanied when visiting their GP. With respect to the former, managers erred on the side of respect for choice, while speaking vaguely about the need to educate residents. In the case of the latter, the issue turned on the severity of a resident's impairment (not illness), and the manager's commitment to the promotion of independence. Relations with GPs were described positively, in part because many managers described long-standing relations between individual residents and their GP. All the managers were using health action plans, although some scepticism was expressed as to their value; were GPs reading them and would the contents of these plans be integrated with the results of annual health checks? The specialist learning disability service was clearly identified as being there to address those health needs most clearly associated with a person's learning disability (challenging behaviour, mental health problems and epilepsy). There were, however, complaints that this service was poorly organised and was no longer

offering some services, for instance, specialist physiotherapy for people with multiple physical disabilities. Secondary care in hospitals was severely criticised for neglecting the basics of care (toileting and eating and drinking) and it was generally seen as being desirable to accompany residents into hospital. This was, however, seen as both problematic and of doubtful value as it meant a reduction in the number of staff available to work in the residential home, and information about a patient that a support worker could offer was not generally requested by hospital clinicians.

GPs identified communication as the main problem when consulting with patients who had a learning disability, and preferred it if these patients were accompanied by a carer who was able to sort out any miscommunication. GPs, beyond the expectation that consultations with these patients would require more time, were not making any other special arrangements for them. All but one of the GPs we interviewed were aware of the introduction of annual health checks for people with moderate and severe learning disabilities, although not all of those who knew about the scheme had introduced the checks, despite the financial incentives and having undergone the mandatory training. Other than organisational inertia, it was not apparent as to why this was the case. Most GPs were aware of health action plans, but only two reported having actually seen such a plan and, in both cases, the GPs said they were unclear as to their precise purpose and what information they should contain. Opinion as to the role and utility of the specialist learning disability service varied. Some GPs said they referred patients to mainstream specialist services because of faster response times, while others preferred the specialist learning disability service because it was thought to be better able to meet the needs of patients with learning disabilities.

The learning disability nurses in the specialist service were particularly proud of their expertise with this population's disability-specific health needs (reflux, epilepsy, mental health problems, and challenging behaviour) and their abilities to communicate with people who had a learning disability. Their role, as they saw it, involved providing healthcare as a member of a multi-disciplinary specialist health service, and educating support workers (in both residential and day services) in recognising and responding to common health problems. However, the learning disability nurses we spoke to were troubled by the fact that they were doing less clinical work, and increasingly being expected to assist local authority care managers by assessing whether or not a person meets the local authority's eligibility criteria for adult social care. This loss of clinical responsibility, and informal co-option into adult social services, was deeply resented. With respect to the health of a person with a learning disability, these specialist nurses believed that the social circumstances of the person with a learning disability were of crucial importance. The health of people living in residential accommodation, despite having more significant impairments and more complex health problems, was thought to be better managed than the health of less severely impaired people who lived independently, as there was less risk of self-neglect. The nurses reported that local authority care managers, as a result of their commitments to independent living, consistently overestimated the abilities of people to manage their own health. Despite having to work closely with staff in adult social services, the nurses described a history of professional rivalry between the two organisations. The introduction of annual health checks was seen by the nurses as very likely to increase GPs' awareness of the health risks this group of patients experienced, although the introduction of these checks was thought to have been hampered by poor communication between the Primary Care Trust (responsible for

commissioning GP services) and the local authority. Commenting on their relations with hospital-based nurses, the learning disability nurses were of the opinion that their counterparts in the hospital had little understanding of the special needs of patients with learning disabilities, and furthermore that these two branches of nursing, as well as having little in the way of shared understanding, rarely communicated.

Care managers in the LDP described their principle responsibility as assessing people's eligibility (with respect to severity of need) for adult social support paid for and commissioned by the local authority. This responsibility, they believed, was a cause of tension with members of the specialist health service. A further complication was that the health team provided only for those adults who meet criteria for a learning disability, while care management was available to all adults judged to be vulnerable (irrespective of whether they had a learning disability) if their social care needs were thought to meet criteria for being substantial or critical. This operational distinction within the same organisation, the LDP, exacerbated cultural and professional differences between clinicians and social workers - differences that were thought to be further ratcheted up by chronic under funding of the LDP. Nevertheless, care managers, like the learning disability nurses, believed a person's social circumstances crucially determined their ability to access healthcare, in that people with milder disabilities living independently were at considerable risk of self-neglect. Care managers saw staff in residential accommodation as having responsibility for monitoring residents' health, but were critical of their efforts at health promotion. For example, residents were not being taught to cook or what constituted a healthy diet. They acknowledge, however, that staff in these homes are caught between respecting residents' poor choices and enforcing health options. With

respect to primary care, GPs were thought to have a good grasp of the needs of patients with learning disabilities, especially where a relationship had been built up over a number of years. Nonetheless, concerns were expressed at the possibility that people with a learning disability might be missing out on routine health screening programmes. Care managers held the view that, when in hospital, people with learning disabilities received poorer care than other patients due to communication problems and misunderstandings of the legal procedures for making substitute decisions. These problems were attributed to hospital staff's lack of experience and formal training in caring for patients with learning disabilities. It was acknowledged, however, that communication between the LDP and local hospitals could be improved as, at present, there was little or no information sharing even when a patient's admission was planned. The views of vulnerable patient leads on the quality of in-patient care were similar to those of the other respondents: clinicians were unaware of their duties under equalities legislation and the MCA; and patients with learning disabilities were not well supported because clinicians lacked experience caring for this group of patients. In addition, the four hospitals in the area covered by the LDP had yet to introduce procedures for identifying and tracking patients with learning disabilities - their efforts were focused on supporting the wider population of vulnerable patients. At the time the interviews were conducted, one of the hospitals was advertising for a learning disability liaison nurse, although all the vulnerable patient leads thought that the needs of patients with learning disabilities were yet to become a priority issue. Establishing links with specialist learning disability services was seen as a good idea as it was imagined that staff in the specialist service could offer advice on how best to support patients with a learning disability. In this regard patient 'passports' were thought, in principle, to be a good idea, despite doubts being

expressed as to whether clinicians would have sufficient time to read them. In the opinion of the vulnerable patient leads, the key determinate of a successful stay in hospital for a patient with a learning disability was whether or not they were accompanied by a carer who could advocate for their needs.

Our small-scale study has limitations, not least the sample size and the absence of people with learning disabilities and their supporters. Recording respondents' answers by hand meant we lost some of the subtlety of their views, and we had to take those views at face value (Silverman, 2001). Nonetheless, through a process of triangulating (Denzin, 1978) it is possible to build up a picture of healthcare for men and women with learning disabilities that spans residential services, primary care, a specialist learning disability service, and secondary care in acute general hospitals.

From the views of all the professionals interviewed it is clear that the quality of healthcare received by people with learning disabilities depends crucially on the support they have from others. Managers of residential homes described the importance of monitoring residents' health and arranging appointments with GPs. As an aid to communication, GPs said they preferred patients with learning disabilities to be accompanied during consultations. The expertise of those working in learning disability services lay in their ability to help people with learning disabilities to communicate and, like care managers, they believed that the health of people living independently (who have less support) was at risk due to self-neglect. Vulnerable patient leads also thought that patients who were accompanied by a carer had a more successful stay in hospital. These different forms of support are potentially augmented by health action plans and patient-passports that ease the transfer of

patient-information between professionals. Consequently, these initiatives are most likely to improve both patients' access to healthcare if the health and social professionals using them understand each other, and have well established lines of communication. Rather worryingly our data suggest such lines of communication exist only between residential homes and GP surgeries. Crucially, there appears to be little communication between residential homes and acute hospitals, and between the specialist learning disability service and acute hospitals. As a result, information regarding the specific needs and (dis)abilities of complex patients is lost to hospital-based healthcare practitioners who are not known for their willingness to engage with carers (another source of this information). From this perspective the introduction of annual health checks and their increased use (Emerson & Glover, 2010), while potentially ensuring that more health problems are detected, and detected earlier, may have less value where treatment involves admission to hospital.

The special needs of men and women people with learning disabilities were recognised by all of those we interviewed, and the existence of specialist learning disability services, when mainstreaming is the norm (Department of Health, 2001), is an explicit recognition that this population is considered to have distinct health needs. However, from the different perspectives of those we interviewed, the utility of this specialist service appears doubtful. The managers of residential homes described the specialist service as disorganised, and the vulnerable patients leads reported that they had no formal links with the specialist service despite their acknowledged lack of experience supporting people with a learning disability. The views of the learning disability nurses and care managers in the LDP are also a cause for concern. The nurses described spending increasing amounts of their time assessing people's

entitlement to local authority services as opposed to administering to their health needs. For their part, care managers described strained relations and professional differences with their clinical colleagues. Moreover, both the learning disability nurses and care managers, albeit in slightly different ways, described a tension between national learning disability policy with its goals for choice and autonomy (Department of Health, 2009), and what was thought to be good for a person's health. For the learning disability nurses this tension arose where people with milder disabilities were encouraged to live independently despite lacking the ability and/or the support to look after their health. For the care managers this tension arose in residential settings where respecting the residents' dietary choices was rarely compatible with promoting healthy lifestyles. In effect, learning disability nurses, care managers, and managers of residential homes are, as others have noted (Johnson, Walmsley, & Wolfe, 2010; Pilnick, Clegg, Murphy, & Almack, 2010; Redley, 2009), caught between potentially competing organisational imperatives: promoting independence and choice while also having to be mindful of a vulnerable person's needs.

In summary, what our small-scale study reveals is that access to healthcare for people with learning disabilities is marked by a need for support, that continuity of support across residential care and the three arms of healthcare (primary, secondary and specialist) requires boundary crossing in the form of interagency communication and information sharing, and providing that support requires an ability to reconcile organisational imperatives to promote both autonomy and health. Given these demands it is hardly surprising that innovation and good practice stems from the actions of committed and energetic individuals, whom Mencap's *Getting it right*

campaign (www.mencap.org.uk) seeks to support. Nonetheless, serious consideration must be given as to whether the support identified by those we interviewed as being central to enabling people with learning disabilities to access healthcare is supported by the recommendations made in *Healthcare for All*.

Understanding access to healthcare

There is a danger that, in the controversy and uncertainty surrounding current reforms of the NHS, the views and interests of people with learning disabilities will be overlooked, and the political capital accrued by *Death by Indifference*, along with that of *Healthcare for All* and *Six Lives* will be lost. Nor is there any real guarantee that the changes to the commissioning and regulation of health services, as endorsed in *Valuing People Now*, will result in the ‘reasonable adjustments’ needed by patients with learning disabilities. The recent scandal at the Mid Staffordshire NHS Foundation Trust (Francis, 2010) has signalled the limitation of regimens of regulation and inspection: all too easily they become tick-box exercises generating their own reality (Power, 1997).

Notwithstanding these concerns, there is a significant difference between the recommendations accepted in *Valuing People Now* and what we were told by the professionals we interviewed. This difference lies in the distinction between making ‘reasonable adjustments’ to a service and supporting someone to access a service. The former is a legal duty arising from equalities legislation, a duty that healthcare providers should have greater regard for (*Healthcare for All*, recommendations: 6, 8, 3), with compliance being a matter of regulation, inspection, and public record (*Healthcare for All*, recommendations: 7, 10). Whereas the latter, supporting a person

to access a service, is a more intimate activity, at its best it involves: directing someone towards making healthy choices, ascertaining ‘where and how it hurts’ despite communication difficulties and challenging behaviour, providing assistance and reassurance during examinations and treatments, and representing a person’s needs and (dis)abilities to clinicians. While this support undoubtedly falls under the purview of: legally enforceable reasonable adjustments; the provision of communication aids (such as health plans and patient passports); improved staff training, and could even be incentivised (like annual health checks), it is not coterminous with a legal enforceable duty. This is not to underestimate the impact that legally enforceable duties could have upon the healthcare of disabled patients, but rights cannot legislate for interpersonal intimacy: the care, consideration and personal regard that one person may hold (or withhold) from another (Reinders, 2008). Health rights for this highly dependent population, in the absence of interpersonal intimacy and positive regard, will not result in quality care (Kittay, Jennings, & Wasunna, 2005). So while providers of healthcare need to ensure their staff receive education and training in learning disabilities and their legal duties under equalities legislation, they also need to consider whether their care practices enable staff to (i) form respectful relations with patients with learning disabilities, and (ii) learn from carers (both family and paid support workers) how best to support an individual who has a learning disability. Furthermore, these practices, where they exist, are threatened by the pursuit of efficiency gains: the intensification of staff workloads and the pressure to be more ‘flexible’ with respect to hours and breaks (Redley, 2009). Within hospitals basic care and healthcare are routinely separated through the use of care assistants who, while cheaper to employ than nurses, are less able to recognise and respond to healthcare needs. This fact, coupled to shift patterns where there is a steady turnover

of staff, and hospital clinicians' general lack of familiarity with the special and complex needs of patients with a learning disability also undermines interpersonal intimacy and positive regard towards patients who can be seen as quite 'other' (Goodley, 2011). Moreover, without wishing to deny the special needs of this patient population, it may be that the poorer healthcare they receive is, in fact, part of wider problems within the NHS: increasing numbers of hospital complaints (Roberts, 2010), and evidence of sub-optimal care (Dr Foster Intelligence, 2010; Parliamentary and Health Service Ombudsman, 2011). Interestingly, those championing the healthcare of people with learning disabilities only rarely make common cause with other groups at risk of receiving healthcare poorer than they are entitled too, such as older people (Joint Committee on Human Rights, 2008) and those with mental health problems (Disability Rights Commission, 2005). Despite these rather bleak conclusions it must be noted that mortality rates amongst people with learning disabilities are decreasing: greater numbers of children with severe and complex needs are reaching adulthood, and adults with learning disabilities are living longer (Emerson & Hatton, 2008). In this respect it must be remembered that access to healthcare and materials promoting healthy lifestyles are not the only determinates of health (Emerson & Baines, 2010). Genetic factors, physical environments and social circumstances also play a part (Krahn et al., 2006) and need to be better understood.

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